

*Report of the Interim Committee
on Head Injury*

*An Examination and Recommendations
for Improved Service Delivery
December 15, 1999*

**Legislative Members of the
Interim Committee on Head Injury**

December 15, 1999

The Honorable Steve Gaw, Speaker
Missouri House of Representatives
State Capitol, Room 308
Jefferson City, Missouri 65101

Dear Mr. Speaker:

The undersigned members of the House Interim Committee on Head Injury have completed their charge and respectfully submit this report.

Representative Paula J. Carter, Chair

Representative Vicky Riback Wilson

Representative Amber Boykins

Representative Charles Shields

Representative Jewell D.H. Patek

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Interim Committee on Head Injury

Missouri state representatives were appointed to the Interim Committee on Head Injury by Steve Gaw, Speaker of the Missouri House of Representatives.

Chaired by Representative Paula J. Carter, the committee was composed of five state representatives who possessed knowledge and experience in the following areas: budgeting and appropriations; health and mental health; children, youth and families; elementary and secondary education and critical issues. Select officials from the Department of Health; Department of Mental Health; Department of Social Services and the Missouri Head Injury Advisory Council accompanied the committee during the public hearings and provided insights on service delivery, referrals and technical assistance for members of the committee and the brain injury community.

The Interim Committee on Head Injury held four public hearings in the following locations:

October 18, 1999 Kansas City - Kansas City Regional Center

October 19, 1999 Springfield - Springfield Regional Center

October 20, 1999 Jefferson City -

Missouri State Capitol Building

October 21, 1999 St. Louis - St. Louis Metropolitan Psychiatric Center.

A total of 69 persons testified before the committee; 21 persons were family members, relatives or friends of individuals with a traumatic brain injury; 32 persons were medical professionals, administrators, program officials or service coordinators; 15 persons were survivors of a traumatic head injury and 1 person represented the Missouri House of Representatives.

In the next section, the dimensions of traumatic brain injury and problems affecting the traumatic brain injury community will be discussed.

Traumatic Brain Injury and Problems Identified by the Traumatic Injury Community

Section 192.735 of the 1994 Missouri Revised Statutes defines head injury or traumatic brain injury as:

...a sudden insult or damage

to the brain or its coverings, not of a degenerative nature. Such insult or damage may produce an altered state of consciousness and may result

in a decrease in one or more

of the following: mental,

cognitive, behavioral or

physical functioning resulting

in partial or total disability.

Cerebral vascular accidents, aneurisms, and congenital defects are specifically excluded from

this definition...

The etiological factors of a traumatic brain injury are motor vehicle accidents, falls (particularly by the elderly), violence (firearms and domestic) or conditions which deprive the brain of oxygen. A traumatic brain injury can occur as a result of open head injuries or closed head injuries and the severity of a traumatic head injury can range from mild to severe. Individuals with such injuries often experience post-traumatic brain injury complications which include physical limitations, cognitive difficulties and psychological difficulties.⁽¹⁾

Individuals and families who testified before the Interim Committee verified the etiological factors leading to a traumatic brain injury (particularly motor vehicle accidents) and repeatedly stated that each individual case of traumatic brain injury is unique. During the public hearings, individuals with a traumatic brain injury and family members living with a person with a traumatic brain injury also identified various issues and problems they have experienced while seeking state services. Such issues and problems included social and behavioral problems experienced by individuals with a traumatic brain injury; the need for increased educational awareness of traumatic brain injury for educators, physicians and families; the mis-diagnosis of traumatic brain injury and secondary characteristics; the lack of alternative housing arrangements for persons with a traumatic brain injury; questionable standards of care for persons with a traumatic brain injury who are placed in nursing homes; transportation problems (particularly in rural communities and isolated areas); the need for greater service coordination; the need for increased funding for traumatic brain injury services; the lack of home and community based services in certain areas in Missouri; and the effect of the Medicaid spend-down requirement, which places a financial hardship on persons with a traumatic brain injury who seek to maintain employment.

Service providers, service coordinators, program administrators and medical professionals also testified before the Interim Committee and identified various problems and issues, which included the need for the Home and Community Based Waiver; the lack of long term care programs for persons with a traumatic brain injury; problems with a change in the prior authorization requirement by the Department of Health; the increasing incidence of traumatic brain injury experienced by newborns (i.e., Shaken Baby Syndrome); establishing a Traumatic Brain Injury Trust Fund; increasing funding for traumatic brain injury services; problems with transportation; the lack of affordable housing for persons with a traumatic brain injury; the need for greater service coordination; the lack services for traumatic brain injury patients in rural communities and the need for telemedicine in rural areas.

While it is impossible to address each issue and problem articulated during the public hearings, the Interim Committee on Head Injury will address (1) the designation of a lead state agency; (2) the need for greater educational awareness; (3) the lack of appropriate treatment and services; (4) funding for traumatic brain injury services and (5) the continued monitoring of persons with a traumatic brain injury. An examination of each issue will be contained in the Recommendations Section of this report.

In the next two sections, the demographics of traumatic brain injury, financial expenditures and current state programs for traumatic brain injury will be examined.

The Demographics and Costs of Traumatic Head Injury

The problems identified by individuals, family members, providers, service coordinators, administrators and medical professionals could be compounded by the increasing number of persons experiencing a traumatic brain injury, the increased demands for traumatic brain injury services and the fragmented nature of the service delivery system for persons with a traumatic brain injury in the State of Missouri.

Demographics - National

Although the lengths of stays in hospitals and the mortality rate of persons with a traumatic brain injury have decreased in recent years due to increased and effective emergency care, effective transportation to specialized treatment facilities, and advances in acute care management, the National Institutes of Health has estimated that nationally, 2.5 million to 6.5 million persons are currently living with a traumatic brain injury and an estimated 1.5 to 2 million persons incur a traumatic brain injury yearly due to motor vehicle accidents, falls, acts of violence and sport accidents in the United States. ⁽²⁾

Further, the National Institutes of Health state that 70 ,000 to 90,000 persons incur a traumatic brain injury resulting in a long term substantial loss of functioning and approximately 300,000 persons are admitted to hospitals with a mild or moderate traumatic brain injury. Traumatic brain injuries affect males twice as often as females; and the incidence is highest in the 15 to 24 year old age category and the 75 year and older age category and is a leading cause of long term disability among children and young adults. ⁽³⁾

The National Institutes of Health further state that the economic impact of traumatic brain injuries in the United States "is enormous." The annual cost of acute care and rehabilitation for new cases is estimated at \$9 billion to \$10 billion. Estimates for the average lifetime cost of care for persons with a severe traumatic brain injury can range from \$600,000 to \$1,875,000. ⁽⁴⁾

Demographics - Missouri

In Missouri, the Center for Health Information Management and Epidemiology reported that 4,280 individuals experienced a traumatic brain injury in 1996. ⁽⁵⁾ Similar to data reported by the National Institutes of Health, the

Center for Health Information Management and Epidemiology reported that males experienced a higher number of head injuries (2,795) than females (1,485) and males experienced a higher incidence rate (108/100,000 persons) than females (54/100,000 persons). Individuals aged 15-24 years old had the highest incidence rate (133/100,000 persons) and persons aged 65 and over had the second highest incident rate (118/100,000 persons). African Americans and other persons of color had a higher incidence rate (96/100,000 persons) than White Americans (77/100,000 persons) in Missouri. The etiological factors resulting in a head injury in Missouri (ranked in the order of highest occurrence) in 1996 were motor vehicle accidents, falls, assaults, self inflicted and other. ⁽⁶⁾

Demographic data obtained from the four Missouri agencies providing services to the brain injury community revealed the number of persons who have received services. The Department of Health (including divisions within the department) enrolled 535 persons at the end of fiscal year 1999. The Department of Health also reported that of the 535 persons enrolled, 380 persons were financially eligible to receive rehabilitation services. ⁽⁷⁾ Officials at the Department of Elementary and Secondary Education, Division of Vocational Rehabilitation stated that 1,427 persons received services for federal fiscal year ending September, 30, 1999. ⁽⁸⁾ Officials at Division of Special Education, reported that 287 persons aged 5 years old through 21 years old received services as of December 1, 1997 and 292 persons aged 5 years old through 20 years old received services as of December 1, 1998. ⁽⁹⁾

Officials at the Department of Mental Health reported that as of fiscal year ending 1997, 190 persons received services. ⁽¹⁰⁾ Officials at the Department of Social Services, Division of Medical Services, stated that for fiscal year 1998, 144 persons with a traumatic brain injury received services through their primary program for persons with a traumatic brain injury, the Comprehensive Day Rehabilitation Program. For fiscal year 1999, 162 persons received services through the Comprehensive Day Rehabilitation Program. ⁽¹¹⁾

Costs - Missouri

Financial data on treatment costs for persons with a traumatic brain injury by agency and/or program was provided by the Department of Health, the Department of Social Services, the Department of Mental Health and the Department of Elementary and Secondary Education, Division of Vocational Rehabilitation.

The Department of Health, Bureau of Special Health Care Needs reported the total general revenue appropriations for

the stated years as follows:

FY 1998: \$723,993

FY 1999: \$932,993

FY 2000: \$982,993 ⁽¹²⁾

For fiscal year 2000, the Department of Health, Bureau of Special Health Care Needs is requesting an additional \$441,381 supplemental appropriation for the purposes of funding supportive services for individuals with a traumatic brain injury. The supplemental budget request for FY 2000 was due to increased costs of services provided and the increased demand for services. The supplemental budget request will be discussed at the end of this section. ⁽¹³⁾

The expenditures of the four most expensive programs reported by the Department of Health, Bureau of Special Health Care Needs for fiscal years 1998 and 1999 were:

1998 1999

Functional Living

\$125, 905 \$125,598

Transportation

\$116, 931 \$280,056

In-Home Supports

\$221,705 \$271,380

Day Activities

\$116,194 \$274,306 ⁽¹⁴⁾

Officials at the Department of Health, Bureau of Special Health Care Needs also reported that the average number of services received per patient and the average cost per patient with a traumatic brain injury has increased. The average number of services per patient and the average cost per patient are as follows:

Average Number of Services

1996 1.67

1997 1.68

1998 1.77

1999 2.09

Average Cost Per Patient

1996 \$2,189.79

1997 \$2,723.72

1998 \$3,419.18

1999 \$3,936.68⁽¹⁵⁾

For fiscal year 1997, officials at the Department of Mental Health reported expenditures of \$2,434,199 for the 190 persons with a traumatic brain injury who received services.⁽¹⁶⁾

The Department of Social Services, Division of Medical Services reported expenditures for fiscal years 1998 and 1999 for persons who received services through the Comprehensive Day

Rehabilitation Program as follows:

FY 1998 \$828, 879

FY 1999 \$994, 495⁽¹⁷⁾

The Department of Elementary and Secondary Education, Division of Vocational Rehabilitation reported the following expenditures for persons with a traumatic brain injury for federal

fiscal years 1998 and 1999 as follows:

Basic Services

1998 \$1,639,649.31

1999 \$1,686,890.63

Supported Employment

1998 \$163,647.80

1999 \$246,686.26⁽¹⁸⁾

The average cost per case for basic support services and supported employment services as reported by officials of the Division of Vocational Rehabilitation are as follows:

Basic Support Services

1998 \$1,954.29

1999 \$2,042.24

Supported Employment

1998 \$3,557.56

1999 \$4,485.20⁽¹⁹⁾

The second division, Special Education, did not have financial data available at the time of this report.

The Interim Committee on Head Injury made a concerted attempt to obtain the most comprehensive data on the number of persons with a traumatic brain injury who were enrolled and/or eligible to receive state services during the previous two years and expenditures associated with such services.

From the data supplied by the state agencies providing traumatic brain injury services, it is evident that the number of persons with a traumatic brain injury who have received services has increased; the costs associated with such services has increased and the number of services received per patient has increased (as reported by the respective agency or division).

The effect of the increases in the number of persons requesting services and costs associated with such services caused the lead state agency for traumatic brain injury services, the Department of Health, Bureau of Special Health Care Needs, to institute measures which resulted in the non-payment of some service providers effective July 1, 1999, establishing a waiting list for new enrollees and requesting a supplemental appropriation for FY 2000. The measures negatively impacted some service providers (i.e., non-payment) and persons with a traumatic brain injury who were seeking and/or receiving state services. This issue will be discussed further in the Recommendations Section of this report.

Current State Programs and Service Delivery

The service delivery system for persons with a traumatic brain injury consist of the Missouri Head Injury Advisory Council and 22 programs dispersed among the Department of Social Services, Division of Medical Services; Department of Health, Division of Maternal, Child and Family Health (currently the lead state agency); Department of Mental Health, Division of Mental Retardation and Developmental Disabilities; and the Department of Elementary and Secondary Education, Division of Vocational Rehabilitation and the Division of Special Education.⁽²⁰⁾

The Head Injury Advisory Council was established in 1985 under Executive Order 85-6 by Governor John Ashcroft for purposes of studying and recommending actions for public and private entities on various issues which included identifying the extent of head injury in Missouri; protecting the personal and civil rights of persons with a head injury; identifying appropriate "entry points" for head injury persons seeking state services; and developing head injury preventative education measures.⁽²¹⁾

In addition to Executive Order 85-6, the federal Traumatic Brain Injury Act of 1996 was passed which required states to establish advisory committees as a condition of receiving demonstration grants from the U.S. Department of Health and Human Services, Health Resources and Services Administration. The purpose of the grants is to "improve access to health and other services regarding traumatic brain injury."⁽²²⁾

The U.S. Department of Health and Human Services, Health Resources and Services Administration requires states that receive a planning grant or implementation grant to discuss how they would "enhance access to comprehensive and coordinated services for persons with a traumatic brain injury and their families"; "use existing research based knowledge and development approaches of previous traumatic brain injury grantees in meeting program goals"; and generate support for the "sustainability of funded [traumatic brain injury] projects through legislative, regulatory and policy changes which would promote the institutionalization of traumatic brain injury services for individuals and their families."⁽²³⁾

In addition, states must discuss how they would examine various issues, which include the development and expansion of *core capacity components*

(which include establishing an Advisory Board); designating a coordinating agency; conducting an assessment and developing an Action Plan. ⁽²⁴⁾

In the attempt to "enhance access to comprehensive and coordinated services" and as a condition of receiving a planning grant and an implementation grant, the Missouri Department of Health, Division of Maternal, Child and Family Health (the implementation grant recipient), the Missouri Head Injury Advisory Council (in an advisory capacity) and an Interagency Committee developed a Traumatic Brain Injury Program Matrix which identifies the four main state agencies providing traumatic brain injury services (Department of Health; the Department of Mental Health; the Department of Social Services and the Department of Elementary and Secondary Education); the 22 programs and eligibility requirements; services offered; limitations and funding information. ⁽²⁵⁾

After identifying the various programs for traumatic brain injury, the Interagency Committee identified *gaps and barriers* in the service delivery system and developed *recommendations*. The gaps identified in the matrix included establishing programs for intermediate care; establishing home and community based services; the need for supports for community living; the lack of psychological and substance abuse services in rural areas; and creating behavioral services for crisis management. Barriers identified in the program matrix included the need for greater educational awareness; establishing a special needs assessment procedure during the interview process for persons identified with a traumatic brain injury; the provision of different benefits for persons with a traumatic brain injury who are school aged and those 21 years of age or older; and the lack of supported employment in rural areas. ⁽²⁶⁾

The Interagency Committee also identified the following recommendations which included developing an educational committee to work with the Missouri Bar Association regarding the management of persons with a traumatic brain injury who violate the law and developing an intervention program to prohibit such persons from violating the law; assessing client needs; developing neuro-behavioral, psychological and substance abuse services; developing a data system across departments; evaluating the services received by children and those received by adults; reviewing the transportation agreements; and examining supported employment services. ⁽²⁷⁾

The Interagency Committee also developed an Interagency Action Plan. The Action Plan (which contained recommendations identified in the matrix) is required as a condition of receiving the implementation grant from the U.S. Department of Health and Human Services, Health Resources and Services Administration. The implementation grant is used for the primary objective of "improving and enhancing access to state [traumatic brain injury] services." ⁽²⁸⁾

In the Recommendation Section, the Interim Committee will examine the designation of the lead state agency responsible for coordinating state services. The Interim Committee will also discuss recommendations which will affect the service delivery system in Missouri.

Recommendations

The 1999 Interim Committee on Head Injury, charged with examining the current state structure of service delivery for the traumatic brain injury community in the state of Missouri, respectfully submits the following recommendations. The implications of designating a lead state agency are discussed followed by a recommendation. Additional recommendations will be discussed under the Programmatic Issues subsection.

At the outset, the Interim Committee would like to thank members of the traumatic brain injury community, medical professionals, program administrators, state policy makers (past and present) for participating in the public hearings and for facilitating discussions for improving the life chances of individuals affected with a traumatic brain injury in Missouri.

Designating a Lead State Agency

In Missouri, a major issue which was discussed during a meeting commenced by the Missouri Head Injury Advisory Council and during the public hearings was the designation of the lead state agency responsible for coordinating state services for the traumatic brain injury community. The designation focused on two state departments, the Department of Mental Health and the Department of Health. ⁽²⁹⁾

A key problem confronting the Traumatic Brain Injury Program, irrespective of the location of the lead agency, is the issue of "under-funding,"[which would place a burden on any agency].⁽³⁰⁾ This issue will be examined later in this section.

Department of Mental Health

The Department of Mental Health, Division of Developmental Disabilities currently provides a range of services to persons who have been certified to have mental retardation and/or a developmental disability (which includes a head injury) before the age of 22 years.⁽³¹⁾

An official at the Department of Mental Health, Division of Mental Retardation and Developmental Disabilities emphasized a number of critical issues which would affect the service delivery system for persons receiving services through the division and for persons with a traumatic brain injury, aged 22 years or older who would be incorporated into the division's service delivery system if a state statutory change is made to include persons with a traumatic brain injury.

First, the primary inclusion of persons injured after the age of 22 years with a traumatic brain injury into the Division of Mental Retardation and Developmental Disabilities would be inconsistent with the division's philosophy. The programmatic philosophy of the division is *habilitation*; for the traumatic brain injury community, the programmatic philosophy is *rehabilitation*.⁽³²⁾

Second, the addition of the traumatic brain injury community (persons injured after the age of 22 years) under the Division of Mental Retardation and Developmental Disabilities "would not" result in the immediate provision of services for this population. This population would be placed on a waiting list, currently containing about 1,700 persons who have a developmental disability with an estimated wait time of 2-3 years, subject to the "current head injury appropriation."⁽³³⁾

Third, persons with a traumatic brain injury, who were injured after the age of 22 years would not be eligible to receive home and community based services under the Mental Retardation and Developmental Disabilities Waiver, 1915 (c) of the Social Security Act (which will ensure federal matching dollars) due to the facts that changing the Missouri statute to include persons injured after age the of 22 years would not change the federal statutes pertaining to the mental retardation and developmental disabilities definition and that this waiver is based on the provisions pertaining to intermediate care facilities for the mentally retarded.⁽³⁴⁾

Finally, the brain injury community "is opposed" to having the Division of Mental Retardation and Developmental Disabilities designated as the lead state agency and that "changing" the *developmental disability definition* contained in the Missouri Revised Statutes [could meet] with "enormous controversy."⁽³⁵⁾

In summation, after considering the implications of designating the Department of Mental Health as the lead state agency and changing the Revised Statutes of the State of Missouri to include persons injured after the age of 22 years into the service delivery system, the Interim Committee on Head Injury has determined that revising the Missouri statutes governing the Division of Mental Retardation and Developmental Disabilities and designating the division as the lead state agency could have the potential for disrupting the current provision of services for persons with a traumatic brain injury and would conflict with the guiding philosophy of the traumatic brain injury community. Finally, the designation would go against the wishes of members of the traumatic brain injury community, who are opposed to the potential designation.

Department of Health

In 1991, the Missouri General Assembly passed House Bill 218 and Senate Bill 125 & 341 which established the Division of Injury Prevention, Head Injury Rehabilitation and Local Health Services within the Department of Health. The division served as the lead state agency and was responsible for various programs which included "ensuring that injury prevention and head injury rehabilitation, evaluation, case management, treatment, rehabilitation and community support services were accessible, whenever possible." ⁽³⁶⁾

In 1995, the division was abolished and the responsibilities were assigned to the Division of Maternal, Child and Family Health, which has served as the lead state agency since the reorganization. The main purpose of the lead state agency is to coordinate services provided by various state agencies for persons with a traumatic brain injury in Missouri. The Department of Health also provides a range of services for persons with a traumatic brain injury. ⁽³⁷⁾

To facilitate the coordination of state services for persons with a traumatic brain injury, the Division of Maternal, Child and Family Health has received a Planning Grant and Implementation Grant from the U.S. Department of Health and Human Services, Health Resources and Services Administration. The division is in the third year of the implementation grant which is used for the purpose of achieving the goal of "improving and enhancing access to services for persons with a traumatic brain injury and their families." ⁽³⁸⁾ Currently, the Department of Health has employed a Program Manager for Brain Injury Services who is responsible

(in cooperation with state agencies providing brain injury services) for achieving this goal.

The implementation grant requires the Division of Maternal, Child and Family Health, Bureau of Special Health Care Needs to conduct an *assessment* of persons with a traumatic brain injury and to develop an *action plan for a community based system of care* in cooperation with other state agencies who provide services to persons with a traumatic brain injury. ⁽³⁹⁾

Under the direction of the Missouri Head Injury Advisory Council and the Division of Maternal, Child and Family Health, Bureau of Special Health Care Needs, an Interagency Committee was established which created a matrix of current services provided in the state of Missouri for persons with a traumatic brain injury. ⁽⁴⁰⁾ After identifying the various programs for persons with a traumatic brain injury, the committee developed an Interagency Action Plan, based on the recommendations developed in the program matrix. The Interagency Action Plan is a statewide plan for "developing a comprehensive, community-based system of care which should encompass physical, psychological, educational, vocational and social aspects of traumatic brain injury services and addresses the needs of persons with a traumatic brain injury and their families." ⁽⁴¹⁾

The current designation of the Department of Health, the Division of Maternal, Child and Family Health as the lead state agency follows the traditional medical perspective for treating and rehabilitating persons with a traumatic brain injury.⁽⁴²⁾ However, research has also shown that in addition to the medical perspective, rehabilitation should include vocational rehabilitation, rehabilitation within schools, independent living programs, supported employment, day programs, case management and consumer peer support programs.⁽⁴³⁾ In Missouri, rehabilitative programs are currently in place or have been identified as "gaps" by the Department of Health, Bureau of Special Health Care Needs and cooperating state agencies or are currently being recommended.

During the public hearings, the Interim Committee received materials and heard testimony from officials at the Department of Health that the agency has initiated actions "for improving and enhancing access to services" for the traumatic brain injury community. However, the Interim Committee also heard testimony from some individuals in the traumatic brain injury community (including the Department of Health) that (1) the service delivery system is fragmented; (2) communication across state agencies (*i.e.*, *Department of Health; Department of Mental Health; Department of Elementary and Secondary Education, Department of Social Services and the Missouri Head Injury Advisory Council*) needs improvement; (3) inequities exist in the service delivery system for persons who experience a traumatic brain injury before the age of 22 years and those after the age of 22 years (persons can receive services from the Department of Mental Health or the Department of Health); (4) the change in the prior authorization requirement resulted in the non-payment of some service providers and (5) the service needs of the traumatic brain injury community "were not a priority."

Recommendation: Lead State Agency

As such, the Interim Committee recommends that the State of Missouri **continue to examine methods and program models for improving the integration of services and to coordinate funding and eligibility criteria for persons seeking traumatic brain injury services and to provide a more complete range of services for appropriate rehabilitation and support for individuals with a traumatic brain injury.**

This recommendation may result in a future designation of a new lead state agency or new model *for coordinating* services and funding to improve the service delivery system for traumatic brain injury survivors, their families and for service providers in Missouri; and to improve the communication among agencies and between state agencies and the Missouri General Assembly.

Programmatic Issues

Additional recommendations of the Interim Committee on Head Injury will be addressed in the following areas which include the need for greater educational awareness of traumatic brain injury; the lack of appropriate

treatment and services; funding for traumatic brain injury services and continued monitoring of persons with a traumatic brain injury. The Interim Committee on Head Injury notes that *some* of the recommendations are listed in the statewide Interagency Action Plan.

Greater Awareness of

Traumatic Brain Injury

Members of the Interim Committee on Head Injury consistently heard from members of the traumatic brain injury community that greater educational awareness of traumatic brain injury was needed for medical personnel, educators at the primary and secondary educational levels, families and policy makers in Missouri.

Some members of the traumatic brain injury community testified that when seeking treatment for their traumatic brain injury, they were mis-diagnosed, and at times, prescribed various medications which prolonged their efforts at rehabilitation.

The Head Injury Advisory Council and coordinating state agencies should continue to investigate methods for raising the awareness and implications of traumatic brain injury in the medical community.

Some members of the traumatic brain injury community also testified at the public hearings that increased educational awareness was needed by educators at the primary and secondary levels in order to facilitate the placement of brain injured persons in a supportive and appropriate learning environment.

Currently, efforts to increase the educational awareness among educators have been taken by the Missouri Head Injury Advisory Council and cooperating government agencies (federal and state) through the recent publication entitled

Educational Directions for Students with Traumatic Brain Injury and the publication (developed with members from cooperating state agencies) entitled

Recommendations for Meeting the Needs of Children and Youth with Traumatic Brain Injury.

The State of Missouri, in cooperation with federal, state agencies and the Missouri Department of Elementary and Secondary Education should continue to promote educational awareness among educators.

Finally, efforts to increase the awareness of traumatic brain injury among families with a traumatic brain injury survivor and state policy makers have been initiated by the Missouri Head Injury Advisory Council and cooperating state agencies through the dissemination of various pamphlets and information packets on traumatic brain injury, available programs and state funding sources for persons with a traumatic brain injury (e.g., *Head Injury: Missouri Resource Packet for Survivors, Families and Caregivers* and *Rating Health Care Plans in the Care of Patients with a Traumatic Brain Injury*).

In addition, the Missouri Head Injury Advisory Council has compiled a voluminous resource guide entitled, *Reference Guide* for state legislators, legislative staff and agency officials. The guide contains information and reports on traumatic brain injury, federal and state laws concerning traumatic brain injury, state government organization and federal demonstration grants.

Lack of Appropriate Treatment and Services

The Interim Committee on Head Injury has reviewed the program matrix and Action Plan of the Department of Health, Division of Maternal, Child and Family Health, Bureau of Special Health Care Needs, in conjunction with the Interagency Committee on Traumatic Brain Injury, and agrees that "gaps and barriers" exist in the service delivery system which include the Home and Community Based Waiver; different benefit packages for school aged and persons 21 years and older with a traumatic brain injury; the lack of psychological and substance abuse services in rural areas; the lack of neuro-behavioral services and developing a behavioral unit for crisis management.⁽⁴⁴⁾

Recommendation: Home and Community Based Waiver

The Department of Social Services, Division of Medical Services (with cooperation from the Department of Health, Division of Maternal, Child and Family Health) **should continue to examine the possibilities (e.g., per capita expenditures; needed services, personnel; administrative capacity and simplicity) of applying for a Home and Community Based Waiver from the U.S. Department of Health and Human Services, Health Care Financing Administration, as discussed under Section 1915(c) of the Social Security Act. Various services could be provided to a small group of targeted individuals with a traumatic brain injury as stated in Section 1915 (c) of the Social Security Act or additional services can be determined by the Department of Social Services, Division of Medical Services, subject to the approval of the Secretary of the U.S. Department of Health and Human Services.**⁽⁴⁵⁾

Recommendation: Telemedicine

In the area of developing psychological and substance abuse services for traumatic brain injury survivors in rural areas, the lead agencies (Mental Health, Health, the University of Missouri-Columbia, School of Medicine), cooperating agencies and providers should continue to examine the implications for using telemedicine in rural areas which lack such specialized services.

Recommendation: Children Services

The Department of Health, Bureau of Special Health Care Needs, should continue to examine the provision of traumatic brain injury services and benefits for school aged and persons 21 years or older. The issue was repeatedly raised during the public hearings by individuals from the traumatic brain injury community who stated that such services were inequitable. Further, the Missouri Head Injury Advisory Council has identified issues confronting children and youth in a 1998 report entitled, *Recommendations for Meeting the Needs of Children and Youth with a Traumatic Brain Injury*.

Recommendation: Nursing Home Placements; Crisis Management Services

The Interim Committee on Head Injury was also informed by family members of traumatic brain injury survivors that individuals placed in nursing homes received sub-standard care from some employees. As such, the Department of Health and the Department of Social Services should consider examining this critical issue in greater detail.

The Department of Mental Health and the Missouri Head Injury Advisory Council should continue efforts for developing a behavioral services/crisis management system (in conjunction with the Missouri Bar Association) for persons with a traumatic brain injury who could experience post-secondary conditions such as entering the criminal justice system as indicated in the Interagency Action Plan.

Recommendation: Neuro-behavioral Services; Reimbursement Policies

Regarding the development of neuro-behavioral unit, efforts should be coordinated with the University of Missouri-Columbia, School of Medicine, Division of Clinical Health Psychology and Neuropsychology in order to provide this specialized treatment to traumatic brain injury survivors in the state of Missouri.

To fulfill this effort, the state of Missouri needs to increase the numbers of neuropsychologists in the state by providing incentives for education and practice within the state.

The state of Missouri should also examine funding and reimbursement policies for services required for full rehabilitation for individuals with a traumatic brain injury.

Funding for Traumatic

Brain Injury Services

The appropriation for rehabilitation services to the Department of Health has been a consistent amount of \$588,323 for the last three fiscal years of 1997 through 1999. In addition, there has been an apparent low priority ranking of traumatic brain injury services in the Department of Health, Bureau of Special Health Care Needs.

In spite of these issues, there has been an increase in the number of eligible traumatic brain injury survivors who receive more than one service, an increase in the average cost per patient receiving services and an increase in the costs of traumatic brain injury services which resulted in a change in processing the traumatic brain injury prior authorization requests by the Department of Health (from monthly to quarterly). As a result, 58 clients were placed on a waiting list, denials of requests for traumatic brain injury services occurred and the non-payment of some service providers (this was revealed during the public hearings) also occurred.⁽⁴⁶⁾

As a result, the Department of Health is requesting a supplemental appropriation of \$441,381 FY 2000 which would allow the department to provide services for about 120 individuals.⁽⁴⁷⁾ However, during the public hearings, some service providers testified that payments for services already provided to persons with a traumatic brain injury were terminated.

Recommendation: Funding for Services

As such, the Interim Committee on Head Injury recommends that the Department of Health should request an increase in appropriations for traumatic brain injury services. The department should honor the existing service contracts of service providers who did not receive payment due to the change in processing prior authorizations (provided that the providers followed the correct procedures for filing the claims). The Interim Committee supports the request for supplemental appropriations FY 2000 in order to provide services for individuals with a traumatic brain injury.

Recommendation: Trust Funds

The State of Missouri should explore the creation of a Traumatic Brain Injury Trust Fund (subject to appropriations from the Missouri General Assembly). It had been suggested during the public hearings that Missouri should consider creating a trust fund financed from motor vehicle violations which is currently done in various states such as California and Florida. However, this proposal would require amending the Missouri Constitution (Article IX, Section VII). Currently, funds obtained from motor vehicle violations are deposited into the County School Fund.

Another funding alternative discussed was the utilization of the Missouri Family Trust. This fund is established in the Missouri statutes as discussed in section 402.199 through 402.225 and sections 473.657 and 475.093 *RSMo., Supp, 1999*. Monies contained in this fund cannot be used by state agencies when determining eligibility for Medicaid, "unless prohibited by federal statutes or regulations." The use of this trust is limited to persons eligible to receive services through the Department of Mental Health or for families, friends, and guardians of persons with a "disability" who establish a fund for a beneficiary. Therefore, this source of supplemental funding for traumatic brain injury services should be examined by families, friends and guardians of persons with a traumatic brain injury in order to improve the quality of life for such individuals.

Recommendation: Budgetary Practices and Inter-agency Communication

The Interim Committee recommends that the Department of Health, Bureau of Special Health Care Needs, continue to improve its budgetary practices, prioritization of services and inter-agency communication between the Missouri Head Injury Advisory Council, the Department of Mental Health, the Department of Social Services and the Department of Elementary and Secondary Education who provide services for the traumatic brain injury community.

Continued Monitoring

The Interim Committee on Head Injury recommends that the Department of Health and cooperating state agencies should continue to effectively monitor all causes of traumatic brain injuries in Missouri.

The Interim Committee on Head Injury recognizes that the Department of Health, Center for Health Information Management and Epidemiology receives reports on the incidence of head injuries and spinal cord injuries in Missouri as required by section 192.737 *RSMo.*⁽⁴⁸⁾

The Center for Health Information Management and Epidemiology has published a report on the incidence of head and spinal cord injuries which is entitled, *Missouri Head and Spinal Injury Registry Report, 1996*. This report revealed that under-reporting was a problem and could affect the tabulations of data concerning the incidence of head injuries in Missouri.⁽⁴⁹⁾

It is anticipated that increased educational awareness of the nature of head injuries in the medical community and improved reporting by Missouri acute care hospitals and rehabilitation hospitals will minimize and/or eliminate the occurrence of under-reporting.

As indicated in the Head Injury Program Matrix and the Interagency Action Plan, the Interim Committee also agrees that a data system needs to be developed "across state agencies" in order to facilitate improved communication across departments. The Interim Committee anticipates that the data system will minimize and/or eliminate errors which could occur in the application/eligibility process for persons with a traumatic brain injury; improve record-keeping (e.g., current) statistics; numbers of persons receiving services, the types of services, the number of services and facilitate the development of outcomes measures for persons with a traumatic brain injury seeking rehabilitation.

Conclusion

The Interim Committee on Head Injury agrees that the implementation of the recommendations will facilitate the development of an improved service delivery system for traumatic brain injury survivors, families and service providers in Missouri.

Again, the Interim Committee on Head Injury would like to thank members of the traumatic brain injury community, medical professionals, program administrators, state policy makers (past and present) for participating in the public hearings and for facilitating discussions for improving the life chances of individuals affected with a traumatic brain injury in Missouri.

Appendix C
Staff of Interim Committee
on Head Injury

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Birdie DuffAssistant to Representative Paula J. Carter

Endnotes

1. Missouri. Office of Administration. Missouri Head Injury Advisory Council. *Overview of Traumatic Brain Injury*, p. 4; pp. 11-16.
2. U.S. Department of Health and Human Services. National Institutes of Health. *Consensus Development Conference Statement: Rehabilitation of Persons with a Traumatic Brain Injury, October 26-28, 1998*, pp. 2-3.
3. Ibid., pp. 4-6.

4. Ibid., p. 8. The National Institutes of Health indicates that the figures underestimate the economic burden to families and society because they do not include lost earnings, costs to social service systems and the lost earnings of family members who care for persons with a traumatic brain injury.
5. Missouri. Department of Health, Center for Health Information Management and Epidemiology. *Missouri Head and Spinal Injury Registry Report, 1996, Table 3-A, p. 17*. This number includes the number of non-admitted deaths and individuals admitted to Missouri acute care and rehabilitation hospitals.
6. Missouri. Department of Health, Center for Health Information Management and Epidemiology. *Missouri Head and Spinal Injury Registry Report, 1996, Figures 3, 5, and 6, pp. 4-5*. The actual number of traumatic brain injuries for individuals aged 15-24 years in 1996 was 982; for individuals aged 65 and over was 872. The number of head injuries experienced by White Americans in Missouri in 1996 was 3,609 persons and the number of African Americans and other persons of color who experienced a head injury in 1996 was 650 persons. For the number of head injury occurring in an etiological category, see Tables 3-B, 3-C, 3-D, 3-E and 3-F, pp. 18-22.
7. Missouri. Department of Health, Bureau of Special Health Care Needs. *The Adult Head Injury Program*, October 15, 1999. The 380 persons eligible to receive rehabilitation services for fiscal year 1999 included persons who received services; persons who did not receive services and persons who received services through another agency. The remaining 155 persons were individuals who received service coordination only. In 1998, the total number of persons enrolled in the Department of Health was 379 persons of which 228 persons were eligible to receive rehabilitation services.
8. Missouri. Department of Elementary and Secondary Education, Division of Vocational Rehabilitation. *Traumatic Brain Injury Consumers for the State of Missouri: A Statistical Report FY 1999*. This figure includes the successful and non-successful closures as well as those receiving enrolled at the end of the fiscal year.
9. Missouri. Department of Elementary and Secondary Education, Division of Special Education. *Information on Traumatic Brain Injury, December 1, 1998*. Information for year ending December 1, 1997 was provided by telephone by Ms. Lina Browner, Division of Special Education on November 12, 1999.
10. Missouri. Department of Mental Health. Division of Mental Retardation and Developmental Disabilities. *Information on Traumatic Brain Injury for the State of Missouri, Fiscal Year 1997*. Information for 1998 and 1999 were not available at the time of this report.
11. Missouri. Department of Social Services, Division of Medical Services. *Statistics on Persons with a Traumatic Brain Injury, Fiscal Years 1998 and 1999*. The information was obtained through a telephone conversation with Ms. Diane Tackett, of the Division of Medical Services on November 17, 1999.
12. Missouri. Department of Health, Bureau of Special Health Care Needs. *The Adult Head Injury Program*, October 15, 1999.
13. Ibid.
14. Ibid.
15. Ibid.
16. Missouri. Department of Mental Health, Office of the Director of the Division of Mental Retardation and Developmental Disabilities. *Demographic and Financial Data for Persons with a Traumatic Brain Injury. Fiscal Year 1997*.
17. Missouri. Department of Social Services, Division of Medical Services. *Statistics on Persons with a Traumatic Brain Injury, Fiscal Years 1998 and 1999*. Expenditure information was obtained through a telephone conversation with Ms. Diane Tackett, of the Division of Medical Services on November 17, 1999.

18. Missouri. Department of Elementary and Secondary Education, Division of Vocational Rehabilitation. *Financial Information on Basic Support Services and Supported Employment Services for Persons with a Disability, 1998-1998*. The figures for basic support services were based on 839 persons and 826 persons for 1998 and 1999. The figures for supported employment were based on 46 persons and 55 persons for 1998 and 1999.

19. Ibid.

20. See Appendix A for a complete listing of state services for persons with a traumatic brain injury which was compiled by the Missouri Department of Health, Bureau of Special Health Care Needs, October, 1999.

21. Missouri. General Assembly. 1985. *Joint Interim Committee on Head Injury: Report and Recommendations*, p. B-1.

22. U.S. Government. House of Representatives. *Traumatic Brain Injury Act of 1996, Public Law 104-652*.

23. U.S. Department of Health and Human Services, Health Resources and Services Administration. *Application Guidance for Traumatic Brain Injury State Demonstration Grant Program, September, 1999*, p. 2.

24. Ibid., p. 3.

25. Missouri. Department of Health. Bureau of Special Health Care Needs. *Traumatic Brain Injury Program Matrix, October 1999*.

26. Ibid.

27. Ibid.

28. U.S. Department of Health and Human Services, Health Resources and Services Administration. *Application Guidance for Traumatic Brain Injury State Demonstration Grant Program, September, 1999*, p. 11.

29. The Missouri Head Injury Advisory Council meeting was held September 27, 1999.

30. Missouri. Department of Mental Health, Division of Mental Retardation and Developmental Disabilities. Letter from Mr. John Solomon to Representative Paula J. Carter, 29 September 1999.

31. Missouri. Department of Health. *Traumatic Brain Injury Program Matrix*, October 1999.

32. *State of Missouri, Revised Statutes, 1998, section 630.005 (13)*. Missouri Department of Mental Health, Division of Mental Retardation and Developmental Disabilities. Letter from Mr. John Solomon to Representative Paula J. Carter, 29 September 1999.

33. Ibid., *Solomon*.

34. Missouri, Department of Health, Bureau of Special Health Care Needs. *Traumatic Brain Injury Program Matrix, October 1999*. Section 1915 (c) of the Social Security Act does allow a state agency (i.e., the Department of Social Services) to apply for a *Traumatic Brain Injury, Home and Community Based Waiver*. See the federal statutes, 42 U.S.C., Section 6001 (8), 42 C.F.R., Section 435.1009 and 42 U.S.C.A., Section 1396 n (c).

35. Missouri Department of Mental Health, Division of Mental Retardation and Developmental Disabilities. Letter from Mr. John Solomon to Representative Paula J. Carter, 29 September 1999.

36. Missouri General Assembly, 1991. House Bill 218 and Senate Bill 125 & 341.
37. Missouri. Department of Health, Bureau of Special Health Care Needs. *Traumatic Brain Injury Program Matrix, October, 1999.*
38. U.S. Department of Health and Human Services, Health Resources and Services Administration. *Application Guidance for Traumatic Brain Injury State Demonstration Grant Program, FY 1999*, p. 11.
39. Ibid., pp. 1-4.
40. The Interagency Committee consisted of representatives of the Missouri Head Injury Advisory Council, the Department of Social Services, the Department of Mental Health and the Department of Elementary and Secondary Education, Division of Vocational Rehabilitation.
41. U.S. Department of Health and Human Services, Health Resources and Services Administration, *Application Guide for Traumatic Brain Injury, State Demonstration Grant Program*, September, 1999, p. 3.
42. U.S. Government, National Institutes of Health. *Report of the Consensus Development Conference Statement for Rehabilitation of Persons with a Traumatic Brain Injury. October 26-28, 1998*, p. 12.
43. Ibid., p. 14.
44. Missouri, Department of Health. *Traumatic Brain Injury Program Matrix, October 1999; Interagency Action Plan, September, 1999.*
45. U.S. Government, General Accounting Office. *Traumatic Brain Injury: Programs Supporting Long Term Services in Selected States, February, 1998*, pp. 6-9. For a discussion of the Home and Community Based Waiver, see U.S.C.A. Section 1396 n(c).
46. Missouri. Department of Health. *News Release: Department Will Seek Supplemental Funding For Head Injury Services, 21 July 1999*; Department of Health, Bureau of Special Health Care Needs. *The Adult Head Injury Program*, October 15, 1999; Department of Health, Bureau of Special Health Care Needs, Letter from A. Diane Poole to Traumatic Brain Injury Service Providers, 25 June, 1999.
47. Ibid.
48. This provision contains state statutes pertaining to the Head and Spinal Cord Injury Registry.
49. Missouri. Department of Health. Center for Health Information Management and Epidemiology. *Missouri Head and Spinal Injury Registry Report*, 1996, p. 1.

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Programs for Persons with Disabilities. U.S. Code, Section 6001 (8).